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The Rocky Road to a Dementia Friendly Community

ADI Taipei – April 2013

Introduction

I live in a small hamlet in the remote (**slide**) rural regions of the Highlands of Scotland ... with my husband (**slide**) Andrew ... and Lollipop (**slide**) views of the fields (**slide**)... and the rocks (**slide**) ... and our rambling old garden (**slide**). We retired there thirteen years ago ready to do all the things we'd planned to do before we got too old to do them!

Disaster

And then 7 years ago disaster struck (**slide**)... at age 58 Andrew was diagnosed with vascular dementia. And it was then that I realised we were a dementia family on our own: entirely on our own, with absolutely no support! And it was this long, lonely journey that made me determined no-one should ever have to do this alone.

Speaking out

So after four painful years, I decided to take the coping strategies I'd learned one step further and use them as a basis to speak out (**slide**), at the same time using the Scottish Dementia Strategy as a platform to get our community dementia friendly. When you read the Strategy, it's very clear those at the top know exactly what we need ... the problem is it was simply not reaching us at grass roots.

What is the Dementia Strategy?

What exactly is the Scottish Dementia Strategy and how did we use it to make our community dementia friendly? It seems we have one of the few governments in the world that recognises the urgent need to address the onrushing tsunami of dementia and its Strategy is a living and ongoing one for dementia families. It's based

- on major issues (**slide**) around the support of, care and treatment for dementia families
- while confirming there are certain basic rights to which every Scottish dementia family is entitled.

So what exactly are the issues that made our life in the community as a dementia family so difficult?

- First (**slide**) is the **Fear** of dementia ... and how the myths and the stigma surrounding dementia prevent acceptance of an early diagnosis.
- The second one affecting us was the extraordinary lack of (**slide**) **Information and knowledge** for everyone in our community about how to deal with this dementia journey.
- Next was **Respect and Dignity (slide)** and how the betrayal of respect and dignity for dementia families is probably the single most important reason why
 - there is fear of dementia,
 - why the stigma is so profound and
 - why my husband was in total denial until just six months ago.

I realised we needed to get to the root of this indignity and disrespect and rip it from the heart of our community.

- The fourth issue was around **Support (slide)** - or lack thereof - from the general healthcare services in our area who do **not** always understand how to respond well to dementia families;
- And the 5th issue the Strategy addresses is the need to **teach Caregivers (slide)** that they need to protect their own welfare to enable them to go on caring for their loved ones safely and effectively.

What is the Solution?

So what was the solution? How could I use these 5 key issues (**slide**) to ensure dementia families in our community were put **FIRST**: since my husband and I simply didn't have the luxury of time to wait until the Dementia Strategy reached us, I realised the only chance we had was if as a community we started pushing **upwards** in the hope we'd meet it filtering down.

And so I set about figuring out how to make our rural community dementia friendly.

Credibility

In those early days the hardest element to overcome was the fact that those who made the decisions simply would not listen to a non-professional, despite the fact that I had carefully analysed what was happening to us as a family and in survival mode had developed coping strategies that seemed to work. But because I was simply a caregiver, no-one would listen.

What I needed was credibility (**slide**). So I went back to University and also applied for a Churchill Fellowship (**slide**) which turned out to be the catalyst to everything that has since happened. I had found my credibility.

Asset Mapping

The time had now come (**slide**) to link talents and resources within the community and the first person I approached was a politician elected to local government on the strength of her concerns for the elderly. We mercilessly

- used her extensive public sector knowledge and networking
- to identify,
- compile and
- link local talent and resources.

Community Interest Company

And then we gave ourselves an identity (**slide**), setting up a Social Enterprise, a new breed of company in Britain with the express aim of using profits (**slide**)

- not for personal gain
- but to be ploughed back into the community
- to fulfil our social **vision**,
- and enable dementia families to live life to its full potential.

Greatest challenge ...

Unexpectedly, the greatest challenge was pulling together the public and private sectors. In other words getting people with different philosophies to understand that you needed money to fund social change: (**slide**)

- and that the public sector was not deliberately hiding behind bureaucratic rules, but was rather ensuring total transparency for public scrutiny
- nor was the private sector there to make huge amounts of money for personal gain
- but that the company's mission was to combine the best of both worlds, remaining transparent while cutting through the bureaucracy to ensure sustainable funding for urgent social change.

DFC Collaborative

We now had to make sure our work was informed by the people we had set out to help. In partnership (**slide**) with dementia families, we formed a Collaborative with local agencies, service providers, voluntary groups and businesses who shared our vision of a dementia friendly community.

Together we identified people of influence in the community who had the passion and potential to be dementia capable community leaders

We engaged with them around the dementia agenda and built on the skills, strengths, interests and enthusiasm that people already had (**slide**). And it's amazing how many we actually found in our rural community.

Task Groups

And we established task groups to make dementia friendly visions become reality (**slide**).

Our first task group was set up to work on an **awareness tool**. We recognised that while professional bodies had excellent training programmes around dementia, what we felt was missing was a 'ten minute' awareness introduction to make the man in the street dementia aware, not professionally proficient in dementia knowledge, but simply aware of the illness and how to respond to dementia families.

We soon learned there is no such thing as 'ten minute training', but what we did discover was that this initial awareness education would be the introduction to further dementia instruction from the professionals, particularly Alzheimer Scotland. What we did was open the door.

Other task groups are working on issues around

- Promoting our identity
- Reducing dementia isolation
- Putting local Care Homes at the heart of the community
- Examining telecare services so essential in our remote regions
- Changing the crisis ethos to one of prevention
- And our latest task group will work with our local newspaper - delivered to 97% of residents in our rural area – to run a campaign in conjunction with our awareness education to make all businesses in our rural region dementia friendly. Such a coup!

Voices for Change

To complement the work we do directly in the community, (**slide**) we created a series of online resources to bring together different experiences, views and sources of support:

- **A Dementia Friendly Community (slide)** is our flagship site and highlights progress towards our vision of living well with dementia
- **A Carer's Voice (slide)** was our first website and focuses on the support needs of the dementia caregivers.
- We also have **A Care Home Voice (slide)** to give professional carers as well as residents and their families the chance to have their voices heard.

- And finally **A Dementia Voice (slide)** which offers a dedicated platform and peer support for people with dementia to tell the 'inside story'.

Beacon of Excellence

With all these innovations, our rural community is slowly turning from one with little dementia support into one that is fast becoming a model of excellence (**slide**) and which can be used as a beacon for others to follow:

- like our local Community Centre
- which allows dementia families
- to be *engaged with*
- rather than *isolated from* the community by:
 - regularly running a range of socially inclusive activities (**slide**)
 - and using music and art (**slide**) to bring people together

Rural Memory Lane

In fact we are slowly developing an umbrella concept, something we call a Rural Memory Lane (**slide**) which is designed to bring the dementia strategy to grass roots (**slide**) by drawing together all threads of dementia work being done in the community to

- get to grips with the practical problems of living with dementia
- to showcase good practice and innovation
- ensure there is no duplication of effort
- but above all to allow dementia families to live full lives within the community.

Funding Challenges

Without funding however, as most of us here will have discovered, it is virtually impossible to do these kinds of projects effectively.

A key ingredient (**slide**) seemed to be that once we could show potential funders that projects could be sustainable and they would not have to fund us forever, money started flowing in.

To this end we are developing an online shop (**slide**)

- linked to a mobile van for local sales
- that will not only merchandise our own butterfly products

- but also be a vehicle for moving project merchandise e.g.
 - cakes and jams from a working kitchen ...
 - vegetables and plants from a sustainable garden
 - or refurbished tools from a 'men in sheds' project

Conclusion

In conclusion (**slide**), by volubly speaking out about the loneliness of being a dementia family

- I found a group of like-minded people
- who shared my vision and
- together we are slowly turning our rural community
- into a Dementia Friendly one.

- While we certainly started off on a very rocky footing,
 - by combining business savvy
 - with local resources and
 - locking into the talents, passion and influence of people right there in our villages,

- we really are making our community one
- that fits the profile of the Scottish Dementia Strategy.

Thank you for listening ...(slide**)**

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12th April 2013